

**Centers for Disease Control and Prevention
EARLY HEARING DETECTION AND INTERVENTION
Ad Hoc Group - Teleconference
November 4, 2003**

**Topic: Partner Organization Highlights and EHDI:
Reaching Out to Culturally Diverse Communities**

TO: Ad Hoc Group for EHDI
FROM: Danielle S. Ross
SUBJECT: Conference call information and agenda.
DATE: November 4, 2003

The next EHDI teleconference will be on Tuesday, **November 4, 2003** from 2:00 to 3:00 pm **Eastern** time. Please call in 5 - 10 minutes before the conference starts so we can begin promptly at two. If you have any questions please contact Marcia Victor (MVictor@cdc.gov / 404-498-3036) or Marcus Gaffney (MGaffney@cdc.gov / 404-498-3031)

An internet based captioning service will be available at no charge during this teleconference. If you would like further information or to schedule use of this caption service, please inform Marcus Gaffney (Mgaffney@cdc.gov / 404-498-3031)

Agenda

- I. Welcome
- II. Sheila Sorkin—National Perinatal Association: “Overview of NPA Cultural Resource Guide”
- III. Trish Thomas—Family Voices: “EHDI: Reaching out to the Native American Indian Community”
- IV. Magdalene Castro-Lewis---- National Alliance for Hispanic Health: “EHDI: Reaching out to the Hispanic Community”
- V. Discussion/Question and Answer Period

**CENTERS FOR DISEASE CONTROL AND PREVENTION
EARLY HEARING DETECTION AND INTERVENTION
AD HOC GROUP TELECONFERENCE
November 4, 2003 2:00pm (eastern)**

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>> **LEE ANN RAMSEY:** Good afternoon. This is Lee Ann from CDC. Thank you for joining us this afternoon. I think it is going to be a very informative and exciting conference call. I want to make one announcement before I turn the floor over to our invited speakers, and that is to remind you about the upcoming national early hearing detection and intervention conference, which will be held February 18 through 21 at the Mayflower Renaissance Hotel in Washington, D.C. You can find information on the CDC Website at: <http://www.cdc.gov/ncbddd/ehdi/conference.htm>. You may also contact me directly if you have specific questions. My number is 404-498-3034.

With that said, I'd like to introduce our three speakers and the topic of today's call. We have begun partnering more with the National Perinatal Association. And a few weeks had an opportunity to engage in some discussion, and we learned about a wonderful resource guide that the NPA has developed, on trans-cultural training, for perinatal healthcare providers who realize that it's applicable to all healthcare providers, to parents, to professionals in the field of EHDI.

So we have invited Sheila Sorkin, who is the executive director of the National Perinatal Association based in Tampa, Florida, to talk a little bit about the National Perinatal Association and their mission. And how we are partnering together, and to give you an overview of the trans-cultural training for healthcare providers. Also on the call, possibly from the National Perinatal Association is Barbara Hughes, member of their Board of Directors. I'd like to thank you, and turn the call over to Sheila. After Sheila Sorkin speaks, we will also be talking about how in the field of EHDI, we can reach out to the Native-American Indian community, with Miss Trish Thomas, of Family Voices. Ms Thomas is the parent of two children with special health care needs, one of who is deaf, and lives on the Pueblo of Laguna Indian Reservation in New Mexico. Ms. Magdalene Castro-Lewis, of the National Alliance for Hispanic Health, will then speak. Thank you again for joining us.

I'd like to turn the call over to Ms. Sorkin.

>> **SHEILA SORKIN:** Good afternoon. It is a pleasure to be talking with you this afternoon. This is a unique experience for me. I appreciate Lee Ann's invitation very much. National Perinatal Association began in 1976. We are multidisciplinary group, that include medical and nursing practitioners from neonatology and perinatology, parents, consumers, advocates, researchers, and the entire care team. The association has been through a series of strategic planning sessions, and over the years, started to look at where there were gaps and needs for education. Our primary activity has been our annual conferences, in which we included the EHDI program, at our conference a year ago in Savannah. We recently completed a conference with representatives from the National Center on Birth Defects and Developmental Disabilities in Bethesda. We are currently planning our 2004 conference and intend to invite geneticists as presenters. Through the strategic planning process, we identified in 1995-1996, the need for transcultural education, that there were definitely gaps in care, access to care, including the building and developing of relationships with patients and families and that these were great concerns to our members.

At that point in time, it was a volunteer led initiative. It still primarily is. There was an identification of initial authors for preparation of a publication. Of course, the content of the publication started out with health and illness, pregnancy, prenatal care, labor and birth, and postpartum care. As we started to work with prospective authors, we started to look at very important aspects of understanding different cultures.

That brought us to spiritual characteristics, psychosocial characteristics and included methods of communications. You will find within this Resource Guide, "Trans-cultural Aspects of Perinatal Care: A Resource Guide," that is now published through American Academy of Pediatrics, the newest version was just launched at our conference two weeks ago and again this past weekend at AAP, that we do emphasize communications!

So, the NPA publication very much ties in with the EHDI program and partners. In this new version, we have expanded upon the area of Professional Competency. We have been thinking for quite some time about this, and had started from the Spiritual Competency component, and then recognizing that when any health professional is working with families and patients who have any differences, understanding them as a whole person is of utmost importance. We started to go beyond the spiritual to looking at ourselves, and so we began to explore and have developed a section on Professional Competency as well. That is the newest, exciting component of our publication.

Later on in this call, we will be talking about Native Americans and Hispanics. There are so many different variations. We have tried to raise concerns and issues. But we don't have all the answers in this text. It is really a Resource Guide. Please take it that way that it will be something that will help stimulate you for conversation and understanding with your coworkers as well as with your patients and families. I had sent everyone a summary with the list of the different chapters. I thought that that would be helpful to you, as well. National Perinatal Association has been involving ourselves in care aspects. We have broadened our program from this text to the level of direct education opportunities. In that regard, we have been conducting Grand Rounds for the last two years, and have been presenting at national conferences. We have a variety of practitioners who make these presentations.

As I said, NPA is multidisciplinary. You may have attended a presentation where neonatologists spoke or a nurse midwife spoke or social worker spoke, all presenting material that has been developed and designed by NPA. We also have developed and will be launching in the next year a training curriculum, "Transcultural Education: A Journey to Cultural Proficiency" to enable health practitioners to improve on their journey to cultural proficiency. NPA selected that terminology, because we recognize that this is an ongoing learning process, and we will be helping through building tools and avenues for communication, to improve relationships and effectiveness of care. This curriculum will be personalized based on the individual's and organization's cultural proficiency needs assessments. NPA trained trainers will be enabled to implement a community based training following their participation in our program. Additional information will be available on this new curriculum early 2004 from NPA. Johnson and Johnson Pediatric Institute has supported this curriculum development.

I may have spoken rather quickly, but I am concerned about time. And so I'd like to open the lines, if you have any questions. I welcome the opportunity to meet many of you at the EHDI conference, where we will be presenting in February.

>> **LEE ANN RAMSEY:** At this time, we are ready to begin the question and answer session. If you would like to ask a question, please press star 1. You will be announced prior to asking your question. To withdraw your question, you may press star 2. If you would like to ask a question, please press star 1. One moment.

>> **NANCY SAGER:** I'm from the California Department of Education. My question is regarding deaf culture. I notice on your list you didn't include anything about the language and culture of the American deaf community. I wondered if you would be including that.

>> **SHEILA SORKIN:** I welcome that question. Thank you very much. This is an ongoing project. This version that we have listed with the different chapters listed, is actually the third version of the publication. So we are on an ongoing basis seeking authors. I would welcome anyone to E-mail me at NPA@nationalperinatal.org and make suggestions for prospective authors. I neglected to speak about our editor, Mary Ann Shaw, who has been the editor in chief of the nurse midwife journal for over 25 years. She is a wonderful editor. We welcome your help in identifying new authors for us to work with. Hopefully, as a result of this call, we will have at least one. Thank you.

>> **BARBARA HUGHES:** Thank you very much. Actually, I have more of a comment. I really wanted to expand for the participants, the scope of this wonderful trans-cultural education training curriculum. In the

exciting thing for me, is that it can truly be customized to the needs of the organization and of the community. It can range anywhere from a full two-day workshop, one day, half day, and the focus can be directed towards what your needs are. What I find so exciting about it is it is not just talking about different cultures and characteristics of those cultures, but helping individual providers identify their own cultural background and biases, and do an individual as well as an organizational and community assessment, with the end goal of being that you as a provider group can go out into the community, and let's use deaf culture for example, out into the community, identify leaders and resources in your community, embrace them, and bring them in, and engage them into a conversation about how do we identify and best meet the needs of this culture together. So I wanted to highlight that that's what the trans-cultural education curriculum, training curriculum can do. The resource book is a wonderful partner in that. But I'm very excited that it makes it more meaningful to an organization or community to identify their needs, and then we can help you along the journey to fulfill your goals.

>> **DEBBIE:** I had a question about the resource guide. Can we order that directly from you? And then what would be the cost for that?

>> **SHEILA SORKIN:** The publication order form is on the NPA Website, <http://www.nationalperinatal.org/>. It is ordered through American Academy of Pediatrics. If you are interested in bulk copies, we would appreciate if you would call our office or E-mail me. Our telephone number is 888-971-3295. We will be able to respond to you for book order needs. There are two levels of pricing. One is for AAP members. The other is for everyone else. The regular price is \$49.95. The member price is \$44.95. Thank you for asking.

>> **PENNY HATCHER:** Yes. Hi. Sheila, I'm from Minnesota. We are integrating as many states are their hearing programs with blood spot programs. The question is, in the booklet, someone mentioned deaf culture. But do you have anything on a newborn screening, especially like the blood spot side, as well as genetic counseling, and then again, the cultural aspects of that?

>> **SHEILA SORKIN:** At this point, Penny, we do not have those featured as chapters in our publication. But again, I repeat, I welcome the recommendation, and suggestion of prospective authors. As I mentioned earlier, NPA is an education organization. We revise our plan for conferences annually such as including genetic counselors as part of our planning for our 2004 conference. And every year, we recognize more and more partners that we need to reach out to. So specifically, no, not at this time. It's not included in this publication. However, as Barbara mentioned, in our training program, we will personalize to the entity that we are working with.

>> **PENNY HATCHER:** One more question. What kind of a relationship do you have with the International Childbirth Education Association? A lot of us work with the childbirth educators to share information about newborn screening, both blood spot and hearing in the prenatal classes.

>> **SHEILA SORKIN:** I'm not sure if you are able to jump on this call, Barbara, to respond with me on this. But I know that Barbara is a childbirth educator, of long-standing. And she is one of our trainers. NPA partners with many organizations. This is of course one that we do partner with. But beyond that, we have not had a direct activity work. But again, please, please give me the proper contact person. I'll be happy to follow up, so that we can achieve that goal.

>> **LEE ANN RAMSEY:** Thank you, Sheila. I'm excited about the collaborative relationship we are building with EHDI and the Perinatal Association. Thank you very much. Our next speaker is Trish Thomas. She is a technical assistance network development coordinator for Family Voices. She is also a parent of two children, with special healthcare needs, one of whom is deaf. And with that, she's worked in the area of deaf and hard-of-hearing children with special healthcare needs for over 20 years. Another great thing is that she is trained as faculty with Georgetown's University National Center on Cultural Competency which is relevant to our call today. She lives on the Pueblo Indian reservation in New Mexico. Hearing her perspective on how to reach out to the native American Indian community will be interesting. I'll turn the floor over to Trish. Thank you for being on this call.

TRISH THOMAS: Thank you. Good afternoon, everyone. I also would like to thank Lee Ann and the rest of the EHDI group for having and giving me this opportunity to speak this afternoon. I am TA Network Development Coordinator for Family Voices. We are a national organization of families and friends who organized in 1992.

We speak and educate on behalf of children and who have special healthcare needs. I'm going to give you some very basic ideas and information, and working with and outreaching to people in Indian country. That is a challenge, as there are more than 554 Indian tribes and Alaska native groups each with their own culture and history.

When working with or outreaching to American Indians it is important to identify a local trusted community broker or liaison to assist you. You can begin with asking local community programs, tribal community health representative programs, Head Start Health Coordinators, local early intervention program workers, Special Education and regular education teachers, along with the State Title V CSHCN coordinators, as to who these brokers/liasons might be. In following with most tribal protocols you should send a letter of introduction to the local tribal leader (President or governor as they are called) letting them know who you are and when you plan to be in their community, along with what you are planning to accomplish while there. Often times this letter will be sent on to the tribal program that is dealing with the population you are outreaching to, and most times they will provide you with a contact name and number to assist you in your visit. Looking at alternative methods of outreach such as putting up culturally appropriate flyers (and by culturally appropriate I mean, that the material is written in a manner and language level that is used and understood by the locals, with pictures that are representative of Indians) at the local laundry, gas station, grocery store, cross roads bulletin boards, local Head Start newsletters, penny saver, thrifty nickel, local paper, or places of worship. One on one contact is best when outreaching in Indian country this is where the local broker/liason can help, they can help identify other locals who can carry your message to the target population. It is also important to know that many Indians use traditional healing methods and healers or medicine people. And that use of traditional medicine should not be discouraged. In Indian country family is very important, this includes extended family that could be, aunts, uncles, cousins, friends or even a whole tribe. It is also important that there is in many Indian communities an Indian calendar that is very different from the traditional calendar that is used by all. Again your local broker/liason will be able to assist you with dates and times in Indian country that are closed or off limits to people who are not Indian or from the tribal community. In many Indian villages where I live we have what is called closed village. Meaning that our Pueblo is closed to all but the tribal members who live there and sometimes no one is allowed to come or go until the traditional event is finished sometimes two to four days. This becomes important if you are scheduling an event in or on tribal lands or communities.

Most Indians are very visual, so it is important to have visual aids in your presentations, again they need to be cultural appropriate. Asking your local broker/liason what is appropriate and when and where to meet can greatly expedite your outreach efforts. When my son was first identified with a hearing loss the audiologist and early interventionist were preparing to assist me in telling my extend family that my son had a hearing loss and where he was hearing. When they showed me what they had compiled and written. I knew that my traditional family members would not understand and possibly be turned off by what was going to be presented by the Interventionist. I was very happy that they let me see know what it was first before they made a final decision. I was able to help them in what would be accepted. Because in our language there is not a term for hearing loss or deafness, and being translated in my language would be not having hears and of course he had ears. I asked if they could use a radio to demonstrate what was normal hearing and where my son's was hearing. This worked out great.

(Etiquette): It is important that elders are acknowledged first in any group, direct eye contact is considered impolite and rude, waiting for a break in conversation to speak is the norm and considered a high form of respect for the individual or individuals speaking. It is customary to offer food or drink to all who come into a home in Indian country, to refuse is considered disrespectful, although you may take what is offered with you and not eat or drink it at the time it is being offered. Indian's are big on giving subtle hints, hoping to give you hints as to what is accepted or not and as not to offend or disrespect any one person. There are both patriarchal and matriarchal tribes and it is important to know which, when interacting with them, this will give you a heads up as to who may or may not be present or speaking for the family or child. Indians have a tendency to shake their heads in a positive manner, this is to acknowledge and show the person talking respect and not necessarily an acknowledgement of agreement with what is being said. It's not uncommon for an Indian person to wait to hear what everyone has to say before speaking or making comment. Sometimes comment may not be made until the meeting is at its end or maybe not until the next day when they have had time to digest it and talk it over with family or another Indian before making comment. Again, one on one contact is best, as it allows for the Indian person the time to share and give comment. Traditional Indians honor life experience and educational knowledge as the same and do not consider one better or higher than the other. Being in harmony and having balance in mind, body and spirit is of great importance. The majority of identified disabilities are not

seen as disabilities in Indian Country, what are viewed and considered as disabilities are alcohol and drug abuse, for they take you out of being in control. It is important to ask if you are not sure of something.

>> **LEE ANN RAMSEY:** Thank you, Trish. I find that all to be very helpful information, as we begin developing more materials for different communities about EHDI, and about data collection, and the importance of screening and returning for follow-ups. So I'm sure that there is some information in your presentation that we would like to use here at CDC as we are developing materials. But I'm in D.C. right now and can't view that. But thank you very much again for being on the call. If anyone has any questions or additional information that would you like of Trish, feel free to E-mail me. I can be a liaison to help you get that information. Our last speaker today is Magdalene Castro-Lewis of the National Alliance for Hispanic Health

>> **MAGDALENE CASTRO-LEWIS:**

Comments for this presentation are unavailable. For more information about reaching out to the Hispanic community please visit the National Alliance for Hispanic Health website: <http://www.hispanichealth.org/> .

>> **LEE ANN RAMSEY:** Gosh, you guys did some thorough presentations. Once again, I know we are running short on time. I wanted to thank you so much for being a part of the call, both as participant on the call, and as a presenter. Again, if you need any additional information, or Websites, or need to be put in contact with someone from the call, please let me know. My email address is: LRamsey@cdc.gov . Thank you

(End of call at 2:59 p.m. EST)